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Patients' expectations:

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2015

document version

Publisher's PDF, also known as Version of record

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citation for published version (APA)

Haanstra, T. M. (2015). *Patients' expectations: determinants, mechanisms and impact on clinical outcomes*. [PhD-Thesis - Research and graduation internal, Vrije Universiteit Amsterdam].

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Summary

The primary goal for medical treatment is to achieve the best possible outcomes for each patient. Coming from a biopsychosocial viewpoint not only biomedical, but also social and psychological factors are important in the development, progress, prognosis and outcome of illness and treatment. One of the promising psychological factors that may contribute to health outcomes are patients' expectations. The basic idea is that what the patient expects to happen, has an influence on what actually does happen. There is a long standing history of research on patients' expectations in the placebo, behavioral and health services research fields. While these studies suggest that patients' expectations are a promising avenue of research, a complete understanding of the specific roles that patients' expectations play within a medical treatment setting has not yet been reached. One of the major issues is the lack of an accepted theoretical framework to place patients' expectations within a medical treatment setting. The three research fields mentioned above have worked from separate theoretical models and frameworks. The ultimate goal of expectation research is to be able to use patients' expectations to optimise clinical outcome. However, in order to be able to fully benefit from the role that expectations can play within medical treatment, it is necessary to integrate knowledge from all these three fields. One way of doing this is to establish an heuristic theoretical framework in which perspectives from the three areas are integrated, supplemented by the perspective of the patient. Crow et al. (figure 1) presented a preliminary integrated model in which the expectancy is the central construct. Crow's model describes four possible categories of determinants of expectations and three categories of outcomes that patients' expectations may relate to.

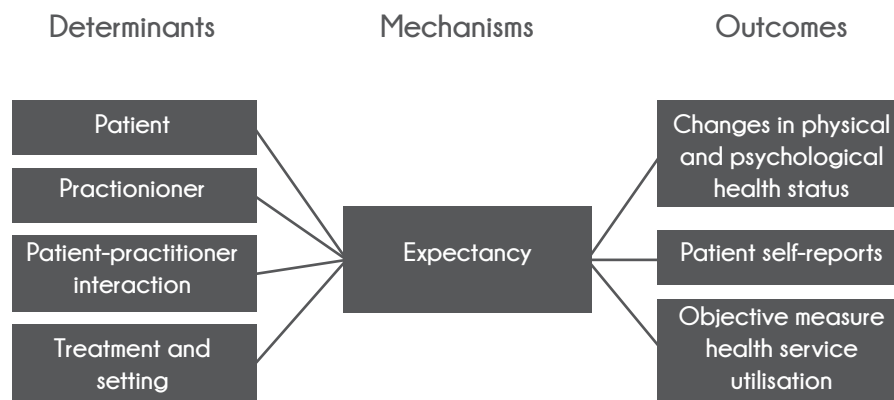


Figure 1: Crow's preliminary framework

In chapter 1 of this thesis we described 4 themes that deserve more attention within the patient expectation research field, namely:

- 1 the definition, typology and measurement of patients' expectations,
- 2 the determinants of patients' expectations,
- 3 the relationship between different types of patients' expectations and treatment outcomes and
- 4 the mechanisms through which patients' expectations influence treatment outcomes.

The aim of this thesis is to advance the scientific understanding of the role of patients' expectations by studying and refining several aspects from the preliminary model by Crow et al. This involved addressing aspects of the four themes related to the role of patients' expectations within treatment settings in chapter 2 to 9 of this thesis.

Chapter 2 of this thesis addressed aspects of themes 1 and 2. We studied how patients with subacute or chronic low back pain conceptualized their expectations regarding treatment. Furthermore we evaluated which factors influenced expectations for low back pain treatment. Data came from pre-treatment interviews with 77 patients with subacute or chronic low back pain that were enrolled in a randomized controlled trial comparing three different interventions. Expectations could be categorized in two main domains: 'outcome' and 'process' expectations, these related to the course of symptoms, and the type of treatment respectively. Within each domain expectations were expressed both as values (what they hoped) and probabilities (what they thought was likely). For individual patients there were differences in the nature (positive vs. negative) and frequency of value and probability expectations. Participants reported that multiple factors influenced their expectations, the most important of which was past experience with treatment.

In Chapter 3 an aspect of theme 1 was investigated. The purpose of this study was to examine whether measurement instruments used to assess the conceptually related constructs expectation, credibility, optimism, pessimism and hope truly measure distinct constructs in patients undergoing an invasive surgery (total hip or total knee arthroplasty; TKA or THA). Patients undergoing TKA and THA (total N = 361; 182 THA; 179 TKA) completed the Life Orientation Test-Revised for optimism and pessimism, the Hope Scale, the Credibility Expectancy Questionnaire for treatment credibility and expectancy. Confirmatory factor analysis was used to examine whether the instruments measure distinct constructs. Theory-driven models with; one, two, four and five latent factors were evaluated using multiple fit indices and $\Delta\chi^2$ tests. The results of the confirmatory factor analysis showed that a five factor model in which all constructs loaded on separate factors yielded the most optimal and satisfactory fit. Posthoc, a bifactor model in which (besides the 5 separate factors) a general factor is hypothesized accounting for the commonality of the items showed a significantly better fit than the five factor model. Based on our primary analyses we concluded that the five constructs are distinguishable in TKA and THA patients. Posthoc, we determined that all constructs, except hope, showed substantial specific variance, while also sharing some general variance.

In Chapter 4 an aspect of theme 3 was investigated by systematically reviewing the literature regarding the relationship between patients' pre-operative expectations, and outcome following TKA or THA. Two different types of expectations, five different outcomes and three different time-points were assessed. English and Dutch language articles were identified through PubMed, EMBASE.com, PsycINFO, CINAHL and The Cochrane Library to September 2012. Articles assessing the association between pre-operative patient expectations and treatment outcomes for TKA/THA in either adjusted or unadjusted analysis were included. The methodological quality of the 18 studies finally included was relatively low. There was great variety in definitions and measurement methods of expectations. No significant associations were found between patient expectations and overall improvement, satisfaction or stiffness. Some studies reported significant positive associations, and others no relationship between expectations and pain and function. We concluded that the relationship between patients' expectations and outcomes in TKA and THA patients is inconsistent.

In Chapter 5 an aspect of theme 3 was studied. It described the expectations that patients have concerning the outcomes of a total hip or total knee arthroplasty and the extent to which each of these expectations are fulfilled 1 year postoperative. Six hundred and sixty-five TKA and THA patients completed the Hospital for Special Surgery Knee or Hip Replacement Expectation Surveys, which queries the expected outcomes for specific functions and activities of daily living. Preoperatively, >60% of patients expected to be much improved or completely improved on 12/19 (TKA) and 19/20 (THA) items. At follow-up, expectations were fulfilled or exceeded in >60% of patients in 17/19 items for TKA and 20 items for THA. In TKA, expectations for 12/19 items were unfulfilled in >30% of patients, with the largest proportions for "kneeling down" and "squatting". For THA the largest proportions of unfulfilled expectations (>30%) were found for: "walking long distances", "walking stairs" and "improve ability to cut toenails". Although for most items >60% patients indicated their expectations were met, a substantial number of patients had unfulfilled expectations which may lead to dissatisfaction with surgery. Therefore, patient education should be targeted at providing realistic information about the expectations most often unfulfilled.

In Chapter 6 another aspect related to theme 3 was investigated. The study explores the predictive value of preoperative outcome expectations on post-operative pain and function in 294 patients undergoing TKA and THA. Two expectation measures; one with general questions about outcome and the other with a list of specific functions and activities were administered to compare their relationships with outcome. The measures were: the Credibility Expectancy Questionnaire which assesses expectations regarding the general outcome of the surgery, and the Hospital for Special Surgery Knee or Hip Replacement Expectation Surveys which assess expectations regarding very specific functions and activities of daily living that are relevant to TKA and THA patients. In this study we also explored the strength of association of expectations as compared to other well-known predictors of outcomes for TKA and THA surgery. Patients' outcome expectations were

consistently part of the combination of variables that best predicted outcomes for both TKA and THA. The amount of variance explained by the total prediction models (including the clinical variables) ranged between 17.0% and 30.3%, with more positive expectations predicting better outcomes. However, the amount of variance explained by the expectation measures alone was limited. Therefore, we suggest that in planning surgical treatment orthopaedic surgeons should take a range of variables into account of which the patient's expectations about outcome of surgery is one. Although the CEQ expectancy subscale predicted outcomes slightly better as compared to the HSS expectation surveys, differences in predictive value of the two measurements were too small to recommend the use of one over the other for prediction purposes.

In Chapter 7 another aspect of theme 3 is explored, specifically we investigated the relative importance of multiple psychosocial factors, above and beyond clinical variables, for predicting treatment success. Variables included; treatment expectancy, credibility, fear avoidance beliefs and locus of control beliefs, in 181 patients with neck pain receiving physiotherapy or spinal manipulative therapy in primary care. Hierarchical logistic regression analyses showed that treatment outcome expectancy predicted outcome success. Expectancies explained 6-18% of variance in the various outcomes above and beyond clinical and demographic variables. Both locus of control and fear avoidance beliefs did not significantly predict any of the outcomes. Our results seem to suggest that treatment outcome expectancy is of potential interest in predicting, and perhaps determining the prognosis of neck pain patients.

Chapter 8 addresses theme 3 but takes a step outside of the field of musculoskeletal disorders. It was concerned with the illness perceptions of 228 patients with type 2 diabetes mellitus (T2DM) and the relationship of these perceptions with changes in the two most important outcomes in diabetes care, those being; self-reported health-related quality of life (HRQOL) and the blood glucose marker HbA1c. Several domains of illness perceptions were measured with the illness perception questionnaire-revised at baseline (T0) and one month (T1): 1) beliefs about how long the illness will last (timeline acute chronic) 2) beliefs about the consequences of the illness (consequences) 3) beliefs about control over self-management (personal control), 4) beliefs about treatment outcomes (treatment control) and 5) beliefs about how the course of symptoms will be (timeline cyclical). Conceptually these domains of illness perceptions are similar to the constructs; outcome expectations, self-efficacy expectations and process expectations as used in the previous chapters of this thesis.

Outcomes were changes in physical and mental HRQOL (SF-12) between baseline and 4 months (T2), and changes in HbA1c between baseline and one year (T3). Hierarchical linear regression analyses were performed to investigate the contribution of early changes in illness perceptions (T0 to T1) to the variance in changes in the outcomes, above and beyond a set of clinical, demographic and psychological covariates. Regression models were repeated with baseline illness perceptions instead of changes in illness perceptions since mean changes in illness perceptions between T0 and T1 were small.

Regression analyses showed that only changes in perceptions about consequences of T2DM contributed significantly to the variance in changes in physical HRQOL. Changes in other dimensions, and baseline illness perceptions did not contribute to the variance in outcomes. Based on these results we concluded that perceptions about the health consequences of T2DM are most promising for future research, they have the potential to act as a target to enhance physical HRQOL.

In Chapter 9 one of the hypothesized pathways that may explain part of the relationship between expectations and health outcomes was investigated. This aim fits within theme 4. Using mediation analyses we examined whether more positive expectations led to better adherence to treatment and subsequently better outcomes for acute low back pain patients treated with paracetamol or placebo paracetamol. This study used data from 1573 acute low back pain patients who participated a randomized placebo controlled trial of paracetamol for acute low back pain. Expectancies were measured with the Credibility Expectancy Questionnaire (CEQ) and adherence with a medication diary. Pain intensity was recorded daily on a 0-10 pain scale and recovery was defined as the first of seven consecutive days scoring 0 or 1 the pain scale. Cox regression (dependent variable: recovery) and linear mixed model analyses (dependent variable: daily pain intensity scores) were performed. The “difference in coefficients” approach was used to establish mediation. There was a small but significant relationship between expectancies and outcomes; 3.3% of the relationship between expectancies and recovery and 14.2% of the relationship between expectancies and pain intensity was mediated by adherence to treatment. In conclusion, the current study does not convincingly support the theory that adherence is a key pathway in the relationship between outcome expectancies and recovery and pain intensity in this acute low back pain population.

In Chapter 10, the general discussion, we discussed the results of the studies per research theme and proposed extensions of Crow’s framework that arise from the results. Furthermore we present promising avenues for further research. The most important findings of the studies described in this thesis are that the literature on patients expectations is very heterogeneous with respect to (amongst others) terminology, types of expectations, measurement approaches, types of outcomes, types of treatments and theoretical frameworks. For several conservative and surgical treatment for musculoskeletal disorders (back pain, neck pain, knee and hip osteoarthritis) however, studies in this thesis consistently showed that patients expectations about outcome, expressed as probability are predictive of patient-centred outcomes (e.g. pain and functioning). This predictive value exists above the baseline clinical status, demographic variables and other relevant psychosocial variables, and although the direction of the effect is consistent (those with more positive expectations have a higher chance of a better outcome) the strength of the association is limited. Still, it may be advisable to assess expectations in clinical settings. Besides helping predict outcomes, assessing and discussing patient’s expectations may also valuable for patient-practitioner communication and shared decision making. However, practitioners should not attempt to predict

outcomes based on a patients outcome expectations solely, but rather a range of factors of which outcome expectations are part. We believe that at this moment it is too soon to recommend specific interventions to alter expectations during treatment in order to achieve better outcomes. Although experimental research shows that such interventions may be promising, translations of these findings to feasible and effective interventions for clinical practice is not easily done. Future research has to establish which expectations are most beneficial in which situations and for which outcomes.